

**A STUDY ON BURDEN AMONG CAREGIVERS OF STROKE
PATIENTS IN HOSPITAL UNIVERSITI SAINS MALAYSIA,
KELANTAN**

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ABBREVIATIONS

HUSM Hospital Universiti Sains Malaysia

KRK Klinik Rawatan Keluarga

SD Standard Deviation

SPSS Statistical package for social science

ZBI Zarit Burden Interview

ABSTRAK

KAJIAN MENGENAI BEBAN DI KALANGAN PENJAGA PESAKIT STROK DI HOSPITAL UNIVERSITI SAINS MALAYSIA, KELANTAN.

Objektif

Kajian mengenai beban di kalangan penjaga pesakit Strok di Hospital Universiti Sains Malaysia dijalankan untuk mengenalpasti tahap beban di kalangan penjaga dan untuk menilai kemungkinan factor-faktor berisiko yang berkaitan dengan tahap beban yang tinggi.

Metodologi

Seramai 116 penjaga kepada pesakit strok telah ditemuramah. Peserta telah dipilih dari Klinik Rawatan Keluarga (KRK). Penjaga di nilai mengenai bebanan menjaga pesakit strok melalui Zarit Burden Interview,

Keputusan

Min beban penjaga adalah 25.42 (SD 6.45). Skor minimum adalah 11 dan maksimum adalah 49. Kajian ini secara signifikan menunjukkan yang penjaga yang menjaga pesakit strok terlantar mempunyai beban yang lebih tinggi. Manakala, penjaga yang mempunyai pendapatan isi rumah yang lebih tinggi dan penjaga yang mempunyai pendidikan bertaraf sekolah menengah atau kolej/university mempunyai beban yang lebih rendah.

Kesimpulan

Faktor berkaitan dengan beban penjaga pesakit strok seperti kondisi pesakit, tahap pendidikan penjaga dan pendapatan isi rumah mesti diambil kira di dalam penilaian beban di kalangan penjaga.

ABSTRACT

A STUDY ON BURDEN AMONG CAREGIVERS OF STROKE PATIENTS IN HOSPITAL UNIVERSITI SAINS MALAYSIA

Objective

This study was carried out to determine the level of burden among caregivers of stroke patients attending Hospital Universiti Sains Malaysia in Kelantan and to evaluate the possible risk factors associated those with burden.

Methodology

A total of 116 caregivers of stroke patients were interviewed. The participants were recruited from the Klinik Rawatan Keluarga in Hospital Universiti Sains Malaysia. Caregivers were assessed for the level of burden using the Zarit Burden Interview.

Results

The mean burden score among the caregivers was 25.42 (SD 6.45). The minimum burden score is 11 and the maximum score is 49. This study significantly found that caregivers who look after bedbound patients have higher level of burden. While caregiver burden is lower with higher household income and among caregivers who have secondary or tertiary education level.

Conclusion

Factors that affect caregiver's burden such as the condition of the patient, caregiver's education level and household income should be taken into account in the evaluation of caregivers' of stroke patients.

CHAPTER 1: INTRODUCTION

1.1 Introduction

Caring for loved ones with medical morbidity such as stroke is associated with several benefits, including personal fulfilment. But for some caregivers, it can cause additional strain or burden in their daily lives.

Caregivers are a group of people most often overlooked even by health professionals. The multiple responsibilities of caregivers include providing physical, emotional and financial support are often at the caregivers' own health and psychological well being. The burden is not just with the activities of caregiving itself but it affects the lives of the caregivers. With the already daily stress of life such as working, looking after other care recipients, the ever rising expenses and personal problems, looking after a care recipient causes more strain.

Studies have shown that burden by caregiving causes deterioration in caregiver's quality of life and could lead to depression (1-3). In the future, we will see more involvement of family caregivers as the population of the elderly are rising, therefore so are the morbidity caused by chronic diseases that increases with aging. Stroke is one such chronic disease that causes high burden to caregivers due to impairment of physical and cognitive function (3-5) . With the advancement in medicine, there are higher numbers of patients surviving stroke than before, but with more disabilities. Due to healthcare costs, we are seeing earlier discharges from the hospitals and home caregiving is still the preferred norm of caregiving in this country. In our country, community health support such as nursing homes or community support workers are still underdeveloped compared to developed countries (6), which are one of the main challenges of Family Medicine Specialists in providing community stroke care (7). Further developments are underway by the government to enhance the healthcare delivery system and

optimise resources (8). Studies have shown that social support is both beneficial for both caregivers' burden as well as improving stroke patients' functional recovery (9, 10).

Screening caregivers for burden will lead to earlier detection and necessary interventions. Identifying the sociodemographic factors of caregivers or patients that are associated with burden will help in identifying those that need regular follow-ups and support.

1.2 Statement of the problem

With the progress of modern medicine, we see more people surviving stroke with a wide range of disabilities, from mild impairments such as mild weakness, cognitive or sensory impairments to marked physical disability that requires extensive assistance in daily living.

Over the years, family caregiving has been affected in a way that caregivers and care recipients are older and have higher levels of disability compared to before. Therefore, the duration, intensity, and burden of care have increased. The financial cost associated with informal caregiving has also risen. In Malaysia the scenario is that large proportion of disabled stroke survivors lives at home and is supported by informal caregivers which are usually family members. Stroke survivors rely heavily on their caregivers' support for daily living. The support they need is not just care in daily living but also in the form of emotional and informational support. It is proven by a study done in Kuala Lumpur among stroke survivor that improving social support, coping style and lifestyle will improve their recovery.(9)

Most Asian countries like Malaysia, family is still the backbone of society. A family member with stroke does not only affect the patient but the family as well. But the person most often affected and overlooked is the caregiver. Stroke patients- caregivers' relationship is a

complex bond. Post stroke patient rely greatly on their caregivers for their well being and survival while such a demand put a heavy toll on their caregivers.

A typical caregiver are usually female and either a wife or a daughter (11-13). Many studies have found that caregivers have poor health outcome and are prone to depression (1, 3). The burden carried by the caregivers often goes unnoticed. By assessing the factors associated with caregivers' burden and issue of depression, those who are at risk can be identified by health providers.

1.3 The rationale of the study

Caregiving burden is an extensive research that has been conducted in many countries for the past 35 years. How each society perceive burden differs from one to the next as a result of sociocultural and religious influence as well as the social support available (14). Therefore, factors affecting burden differs from one population to the next. In Malaysia, caregiving research has just begun to take foot. This might be because Malaysia is also facing an aging population with increasing disabilities (15) due to the improvement of our healthcare over the years. We are seeing more people living longer with diseases seen in the elderly such as heart failure, dementia and stroke, which will be taken care of at home by family members.

Therefore, there is an urgent need to have more data on caregiver's burden in our country.

Most of caregiving researches had been carried out in the capital city. The results from the population of Kuala Lumpur will be different from the population in Kelantan. It differs in many aspects such as the race ratio, level of income, the use of formal or informal support as well as the sociocultural aspect. The purpose of this study is to investigate the level of burden in the population of Kelantan, and to find as well as predict the factors that are significantly associated with burden. We will compare our findings with results from local studies as well as studies from other parts of the world and to see the similarities and differences. This

research is also to provide more awareness about the current situation with our caregivers. This is for us to evaluate our service and to improve to accommodate their needs. This study is also to serve as a guide to help health providers to identify caregivers at risk during follow-up.

CHAPTER 2: LITERATURE REVIEW

2.1 Stroke

Stroke definition

Strokes and transient ischaemic attacks (TIAs) are acute neurological events, presumed to be vascular in origin, produced when cerebral blood supply is disturbed due to occlusion or hemorrhage leading to cerebral ischaemia, cerebral infarction, or cerebral haemorrhage. The symptoms and signs of stroke persist beyond 24 hours or cause death within 24 hours, while with TIA, the symptoms and signs resolve within 24 hours (16).

Stroke can be classified into two types: Ischaemic stroke and Embolic stroke. Approximately 80 percent of strokes are due to ischemic cerebral infarction and 20 percent to brain hemorrhage.

Ischaemic strokes are caused when a blood vessel in the brain is blocked, for example by a blood clot or by the fatty material from an atherosclerotic plaque. The brain cells in the part of the brain served by the affected blood vessel die of lack of oxygen and nutrients. There are two main types of ischaemic stroke: Thrombotic ischaemic stroke and Embolic ischaemic stroke. Thrombotic ischaemic stroke happens when a blood clot spontaneously forms in an artery in the brain. This is a common complication of atherosclerosis. 50% of ischaemic stroke is atherothromboembolism and 25% is intracranial small vessel disease (penetrating artery disease). Embolic ischaemic stroke happens when a part of the fatty material from an

atherosclerotic plaque or a clot in a larger artery or the heart breaks off and travels downstream until it is trapped in a narrower artery in the brain. Embolic strokes are common complications of atrial fibrillation and atherosclerosis of the carotid arteries. Cardiogenic embolism is 20% from ischaemic stroke (16,17).

There are two main types of haemorrhagic stroke which is intracerebral haemorrhagic stroke and subarachnoid haemorrhagic stroke. Intracerebral haemorrhagic stroke occur when there is bleeding from a blood vessel within the brain. High blood pressure is the main cause of intracerebral haemorrhagic stroke. Subarachnoid haemorrhagic stroke occur when there is bleeding from a blood vessel between the surface of the brain and the arachnoid tissues that cover the brain (16-18).

Generally, stroke patients will experience sudden weakness or numbness of the face, arm, and leg, usually on one side of the body; speech may become slurred and the ability to understand others may become difficult; vision may be dimmed or lost, usually in one eye; and other symptoms such as sudden severe headache and dizziness may occur, causing unsteadiness or falls. Specific clinical features of stroke correlate with different part of the circulation affected which is the anterior circulation (middle and anterior cerebral artery) and posterior circulation (vertebobasilar system) (16).

Middle cerebral artery stroke usually present with aphasia, hemiparesis, hemisensory loss, homonymous hemianopia, parietal lobe dysfunction (ie astereognosis, impaired two point discrimination, sensory and visual inattention, left right dissociation and acalculia. Anterior cerebral artery will cause weakness of lower limbs more than the upper limbs (17).

Posterior artery circulation stroke causes features such as cortical blindness, ataxia, dizziness or vertigo, dysarthria, diplopia, dysphagia, horner's syndrome, hemiparesis or hemisensory loss contralateral to the cranial nerves palsy and cerebellar signs (17).

2.2 Epidemiology

According to WHO report 2003, stroke is a leading cause of adult disability (18). As mortality declines, the number of stroke survivors with impairments and disabilities has increased. About two thirds of acute stroke patients will survive the initial stroke and of the survivors, about half are disabled because of persistent neurological impairment(19). Every year, 15 million people worldwide suffer a stroke. Of these, 5 million die and another five million are left permanently disabled. It is anticipated that by 2020, stroke would have moved from the 6th to the 4th leading cause of lost disability adjusted life years (DALY's). It is among the top four leading causes of death in ASEAN countries, with the crude death rate ranging from 10.9 per 100,000 in Thailand to 54.2 per 100,000 in Singapore (20).

In Malaysia, stroke was the top two leading causes of death reported by Malaysian National Burden of Disease Study. The number of DALYs lost per 1000 population for non-communicable diseases including stroke was 101.8 (4). Mortality because of stroke constituted 8.9% in males and 12.1% in females of total certified deaths. Since 2005, the percentage of deaths attributed by stroke in general hospitals has ranged from 6.6% to 8.4% (21).

In Kelantan, admission in HUSM from January 1997 to December 1998, showed that stroke percentage was 86% Malays, 13.9% Chinese. The types of stroke were 56.3% ischemic

stroke, 36.1% primary intracerebral haemorrhage, 7.6% subarachnoid haemorrhage. Mean age for stroke patients in Malaysia between 54.5% and 62.6% years while in Kelantan mean age for stroke is 59.3 years. Risk factors for stroke in Kelantan was smoking, diabetes, heart disease, hypercholesterolaemia and hypertension which is the highest contributor (22).

2.3 Complications of stroke

As a result in advancements in stroke care, the mortality and morbidity rates caused by stroke are declining. However, stroke survivors often suffer from a number of physical, psychological and psychosocial complications. The various effects of stroke are interrelated and influence one another.

The most common complications of stroke are immobility or impaired mobility, weakness or paralysis of one side of the body, loss of energy, fatigue, dysphagia, incontinence, pain, speech and language deficits or aphasia and impaired arm function.

As discussed before that stroke causes multiple type of functional disabilities. Prediction of the functional outcome of stroke survival is useful especially in planning more appropriate short-term and long-term goals for the stroke survivors. In a study done in USM found that younger age and less severe neurological impairment significantly predict good functional status at 6-month (4). While another study done in UMMC found that, functional status of acute stroke patients in this study has improved at 3 months post stroke and significant correlation was seen between the initial severity of stroke and functional status at 3 months post stroke (19).

Sexuality is also affected following stroke, including sexual functioning, libido, sexual arousal, sexual activity, coital frequency and satisfaction with sexual life which was reported

by Korpelainen et al. In his study, they found many aspects of sexuality that were affected: patient's general attitude toward sexuality, fear of impotence, inability to discuss sexuality, unwillingness to participate in sexual activity, and the degree of functional disability. The spouses also reported a significant decline in their libido, sexual activity, and sexual satisfaction as a consequence of stroke (23).

Stroke also causes impairment in language and it depends on the area affected. If the Broca area which is the language centre within the dominant side of the brain was affected, patient will have expressive aphasia. Patients will be speaking in short, meaningful phrases taking great effort to produce, experiencing difficulty to convey thoughts through words or writing and difficulty putting words together in coherent, grammatically correct sentences. They can understand other people normally. If the Wernicke's area which is the language centre located in a rear portion of the brain, was affected, patient will have a type of aphasia that are related to understanding spoken or written language. Patients usually have incoherent speech. Around 20% of stroke patients experienced problems in communication in terms of difficulty to understand or to express language and should receive speech therapy. These physical disabilities can lead to emotional and psychological disturbances such as anger, anxiety, frustration, hopelessness and then, to depression (24).

Depression is a common psychological complication of stroke, which is caused by the sudden onset of disability or loss of body functions experienced by stroke survivors. A study done by Sulaiman et al among stroke patients in UMMC, found that major depression is common 4-8 weeks after stroke. The prevalence of major depression was 36% based on DSM IV criteria. Major depression was associated with left hemisphere brain lesion, significant physical disability with Modified Rankin Scale >2 and previous history of depression (25). Another study by Glamcevski et al also done in UMMC examined specific factors associated with

depression in a stroke population. In their study, 15% of their patient was found to have moderate to severe depression. They found that occurrence of depression was significantly correlated with advancing age, Malays and Chinese in contrast to the Indians ethnic population, non-continuance of pre-stroke lifestyles, and poor performance in the activities of daily living (3). A study done by Nor Azlin et al on health related quality of life showed that with the exception of bodily pain, the mean score of all SF-36 health domains of stroke patients were lower than that of the general population. The greatest difference was in role physical, followed by physical functioning. Female patients demonstrated higher score than the males in all SF-36 domains, in particular general health and social functioning. There were no differences of HRQoL domains after comparison according to post stroke duration (26).

With the rise of survivors, stroke rehabilitation is increasingly playing a pivotal part in post stroke care (19). Recent years have seen increasing awareness of the role of caregivers in the long-term management of stroke patients. It is also becoming clear that the emphasis in stroke rehabilitation needs to shift from a patient-focused approach to a combined patient- and caregiver-focused approach because they are central in preserving rehabilitation and the long-term well-being of stroke survivors (27, 28). Involvement of family is important. Study shows that people who have good social support after a stroke positively associated with good functional status. Hussain et al suggested that stroke recovery program need to involve family support. This is because their study done at UKMMC investigated the factors that influence stroke patients' recovery, found that social support, patient's coping style and lifestyle were the significant relationship with stroke recovery. They define social support as the supportive, loving support with outside activities, opportunities to talk about personal problems, monetary advice with the aim to increase patient's motivation to return to function without hoping for sympathy (5).

2.4 Burden among caregivers following stroke and the associated factors

It cannot be denied that caregivers do carry a level of burden when caring for others.

Caregivers have to deal with not only stroke patients' difficulties in mobility, self-care, and communication, but also their cognitive impairment, depression, and personality changes (29, 30). Because of the severity of stroke and the prevalence of post-stroke complications, as well as the sheer number of stroke survivors requiring care, the burden experienced by caregivers of stroke patients may be substantial. These caregivers may have additional demands from other aspects of their lives, such as having to take care of their own children as well or they may have their own health problems (31).

There is concern that the level of burden experienced by these caregivers may further affect their own well-being and health, whether physically or mentally. A local study done by Tn Zailina et al, 2008 showed that the prevalence of depression among caregivers of patients with dementia is 17.3 % (32), while a study by Morimoto et al, 2003 in Japan showed a prevalence as high as 52% (2).

Therefore, understanding the factors and identification of determinants of caregiver burden will help to target caregivers at risk for physical or mental health problems (29).

A study comparing between spouse, adult children and children in law caregivers show that spousal caregivers provide more support but complain less, making them more prone to depressive symptoms, higher financial and physical burden (33). Another study comparing between spousal, adult children and grandparents caregivers, found poorer health among grandparents caregivers but also found burden among spousal caregivers as well (34).

Prior research on the effect of patients' strokes on caregiver burden and health has found mixed results. Some studies have found worse patient physical functioning to be associated

with higher levels of subjective caregiver burden (35). Often times, however, patient health status does not predict subjective caregiver burden (28, 31), or the relationship is inconsistent across different time points (36).

In the aspect of cultural differences, studies from Korea and Turkey both concluded that in their population, gender of caregivers (female) and being close relative are important factors related to the caregiver burden in their population (35, 37). Due to our social norm, female are more likely to take on or pushed towards the responsibility of caregiving. Perhaps because of this a study by Fatimang et al (11) in Kuala Lumpur, Malaysia was carried out among female caregivers of stroke patients. This study found that the burden prevalence was 37% which is in line with results from Zainuddin et al (38) who researched burden among elderly patients, obtained the burden prevalence of 31%. Comparatively Choo et al (39) in their study on caregiver burden in Dementia patients found that the prevalence of burden was only 5.7%.

Zainuddin et al in their study found that shorter duration of caregiving is associated with higher level of burden and longer duration of caregiving is associated with lower level of burden (38), which correlate with findings from the study from McCulough et al which found that caregiving burden and patients' and caregivers' anxiety levels decreased with time, despite no significant changes in patients' dependence or support levels (28).

Goh et al to assessed formal and informal caregiving for elderly in the Malaysian society under the absence of a structured long-term care environment. They found that private for-profit care providers offer better facilities and services than non-profit centres. Informal caregiving is mainly performed by daughters. This could be the main reason why elderly

prefer informal caregiving. The authors calculated that informal caregiving cost about USD\$330 (about RM 1000) per month. In comparison, formal caregiving can cost more than USD\$330 and vary widely depending on the range and quality of service (40). Since studies shown that majority of caregivers are from the low to moderate income group (5, 11), this study highlight the monthly financial burden when caring for a family member with stroke.

Hussain et al carried out a study to predict the factors that affect the quality of life among caregivers of hospitalised first time stroke patients in Kelantan. They found that family caregivers' health was found to be a significant predictor of life satisfaction among them. The better the caregivers health status, the better will be the caregivers' life satisfaction. Also, stroke survivors older age and lowest level of education were associated with negative score of family caregivers' quality of life (5).

Psychoeducational and psychotherapeutic interventions have been proven to effective in the West (41, 42). Che Rabiah, in her study, explored the educational needs of home-based stroke patients (HBSP) and family caregivers in Kelantan. In her qualitative study, she interviewed family caregivers and health care providers separately. She found that provision of information and education does not meet the needs of many patients and families. The caregivers wanted information on many aspects of stroke such as the nature and impact of stroke; how and why stroke happens; how to prevent stroke recurring; prevention of complications; promoting faster recovery; skills on managing patients at home and religious needs. She suggested the formation of a multidisciplinary stroke team to address these educational needs (43).

2.5 The importance of screening for burden among stroke caregivers

Caregivers are pivotal in the care of stroke patients and their functions are various. They provide informal care providing assistance at home with activities of daily living such as eating, getting in or out of bed or a chair, using the bathroom, dressing, bathing, walking across a room or any help with instrumental activities of daily living including preparing meals, grocery shopping, making phone calls, taking medications, and managing money.

As the elderly population are rising, we will see more elderly will be institutionalised at home. The number of Malaysians aged 60 years and above is estimated to be 1.4 million and is expected to increase to 3.3 million in the year 2020, with the percentage expected to be 9.8% of the population (44). In Malaysia, the current norm is for our elderly or disabled to be cared for at home. In the United States, eighty percent of adults requiring long-term care currently live at home or in the community, and unpaid family caregivers provide 90 percent of their care (45). Therefore, the demand for family caregivers is expected to rise. In the United States it is expected to rise by 85 percent (46).

Informal caregivers are important in the long term care of stroke patients. Their role is increasingly seen as an extension of stroke care after discharge from acute care. The government are now moving away from hospital care as it is seen as being costly, therefore the length of hospital stay is getting shorter. So there is increasing recognition of caregivers role as an effective method to reduce government healthcare costs. From the US data, the availability of a spouse caregiver is associated with a \$28,840 annual reduction in formal Long term care (LTC) spending per additional elderly male. Adult child caregivers are associated with up to \$3,830 less in LTC spending per year (47).

Caregivers are often overlooked during visits to the clinics by health care providers, who are usually more focused on the patient, which is unfortunate as caregiving itself has negative implications on caregivers' health. Apart from that, both caregivers and care recipients are getting older, therefore have higher levels of disability than before. The duration, intensity and personal financial cost has increased. The distress linked to caregiving has been associated with physical and psychological complications such as depression and even death. A study by Schulz et al followed up caregivers of elderly patients over 4 years. They found that over the 12.6% of caregivers who died, those who care with emotional or mental strain are more likely to die than among the non caregiver control group and among caregivers who reported no strain (48).

2.6 Screening for burden

2.6.1 The Zarit Burden Interview (ZBI)

In 1980, Zarit et al in his study of caregiving burden among dementia came up with a 29-item questionnaire to measure the caregiver's perceived burden of providing family care. Since then it had evolved into a revised shorter 22 version which became widely used. The ZBI became even shorter and more convenient to use with the 12 items version (49).

Apart from the ZBI, there are also other numerous tools to assess burden in the burden research (50, 51). However, in this study the 22 items ZBI questionnaire was chosen because it is the most widely used and has been translated into several languages including Malay.

The ZBI was initially developed to assess burden among caregivers for patients with dementia. However, it is proven that this questionnaire can also be used in a variety of other diseases and also different cultures or populations (52, 53).

The 22 items ZBI are assessed on a 5-point Likert scale, ranging from 0 = ‘never’ to 4 = ‘nearly always’. Item scores are added up to give a total score ranging from 0 to 88, with higher scores indicating greater burden. Score values and interpretation are guidelines only.

The questions focus on major areas such as caregiver’s health, psychological well-being, finances, social life and the relationship between the caregiver and the patient (54). The ZBI is a reliable measure with cronbach alpha’s 0.91 to 0.93 (32, 54, 55) and test retest reliability of 0.89 (54). The factor structure of ZBI is unclear with many studies has been carried out to determine this with a variety of results with some finding 2 factors, 3 factors and 4 factors (56). The factor analysis study by Siegert et al (53) on acquired brain injury including stroke found that the ZBI have 3 factors or domains which are:

Domain	Explanation	Items
Personal strain	Psychological distress of the caregivers	1,4,5,6,9,13,14,16,18,19
Role strain	Impact on the caregiver's life	2,3,7,8,10,11,12,15,17,22
Guilt	-	20, 21

Table 1: Domains of the ZBI

The Zarit burden interview has been used in many caregiving studies in Malaysia before (11, 32, 38, 39). In this study, the 22 item Zarit Burden Interview (ZBI) is a translated version of the original. Choo et al (39) translated this questionnaire for their study which was also used in the study by Tn Zailina et al (32) who validated the translated questionnaire in a pretest in HUSM. The reliability was found to be cronbach alpha= 0.91 which was good. Therefore, this questionnaire is also suitable to be used among Malay majority population.

2.6.2 Conceptual Framework

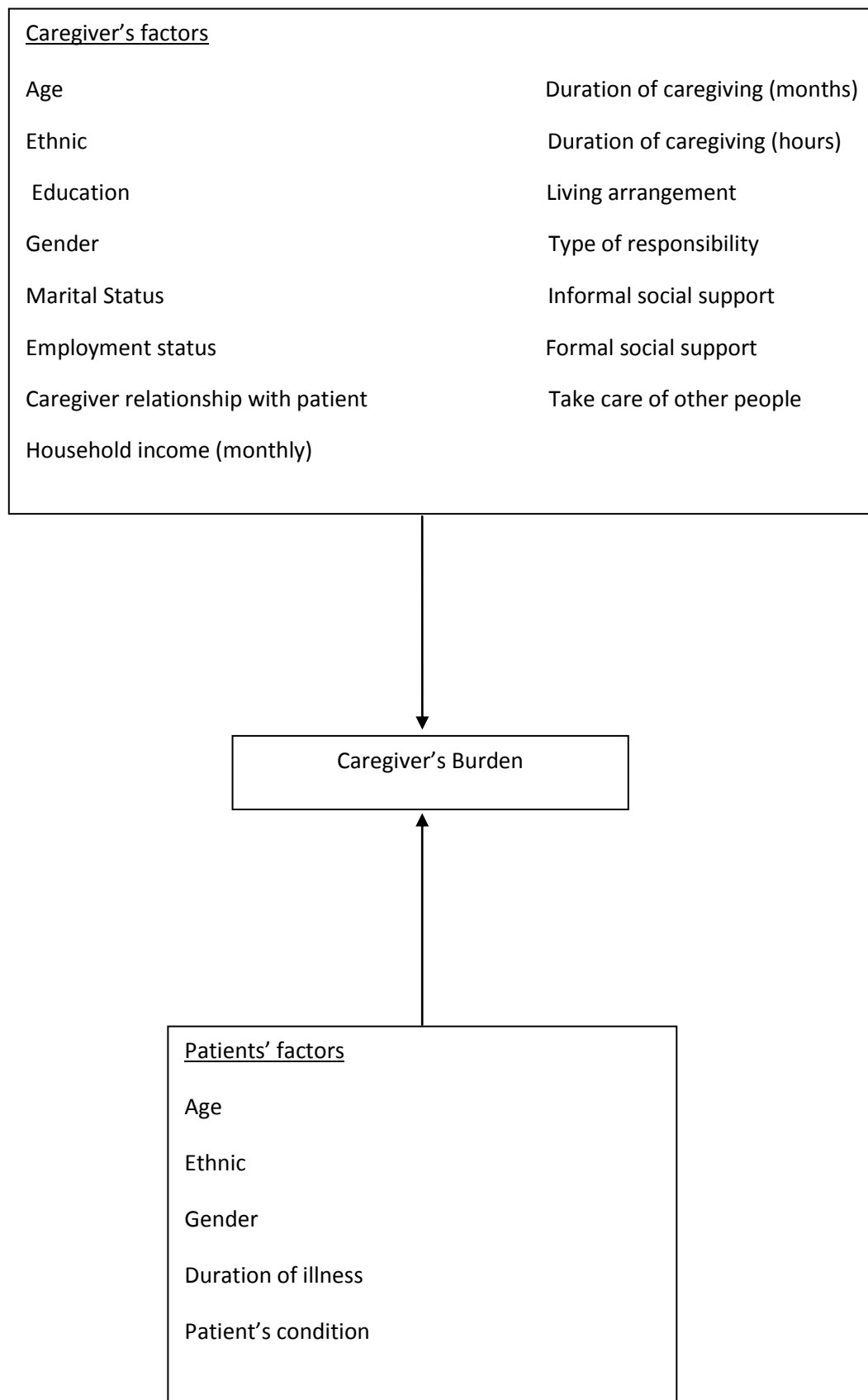


Figure 1: Conceptual framework

CHAPTER 3: OBJECTIVES AND HYPOTHESIS

3.0 General Objectives

To determine the burden perceived by caregivers of stroke patients on outpatient follow-up in Hospital Universiti Sains Malaysia, Kelantan.

3.1 Specific objectives

1. To determine the level of burden among caregivers of stroke patients
2. To determine the associated factors for burden among caregivers of stroke patients

3.2 Research Hypothesis

1. There is a significant burden among stroke caregivers.
2. Caregivers' variables and patients' variables are significant associated factors for burden.

CHAPTER 4: METHODOLOGY

4.0 Study Area/ Background

This study was conducted at the Klinik Rawatan Keluarga (KRK) in Hospital Universiti Sains Malaysia (HUSM), Kelantan. The KRK is the outpatient department that follow-up majority of chronic diseases including stroke patients.

4.1 Study Design

This is a cross sectional study

4.2 Reference Population

All caregivers of stroke patients under outpatient follow up in Kelantan

4.3 Source Population

All caregivers of stroke patients under outpatient follow-up at Hospital Universiti Sains Malaysia from December 2012 - May 2013

4.4 Inclusion Criteria

1. Caregivers of patients with stroke as documented in the medical records
2. Caregivers who are able to understand Malay or English

4.5 Exclusion Criteria

1. Caregivers who were already taking care of patient prior to stroke.
2. Caregivers who were already taking care of patient due to other reasons apart from stroke.

4.6 Sampling method

All caregivers of patients with stroke who came for KRK outpatient follow-up during the collecting data period were identified during registration. There are usually 1 to 2 stroke patients on follow-up at KRK per day. The caregivers who fulfilled the inclusion and exclusion criteria were interviewed separately from the patients to avoid biasness.

4.7 Sample size calculation

For objective 1: To determine the mean score of burden among caregivers.

The calculation is using the single mean formula.

$$n = (Z \sigma / \Delta)^2$$

$Z = 1.96$; standard normal distribution at 95% confidence interval

σ = Standard deviation 13.07 (55)

Δ = precision 3

n = minimum required sample

$$n = [(1.96 \times 14.5) / 3]^2$$

$$= 89.7$$

The sample size of 90 caregivers was required. If 20% non response rate, sample size for caregivers is 108.

For objective 2: To determine the associated factors for burden among caregivers of stroke patients

The sample size calculated using the Power and Sample size calculation (PS) was used for categorical variables.

The calculation of sample size is as follows:

$$\alpha = 0.05$$

$$\text{Power} = 0.8$$

P0 = probability of exposure among controls

P1 = probability of exposure among cases

$$M = 1:1$$

n = sample size

Variables	P1	P0	Minimum sample size (n)	n+ 20% non respond rate
Marital status (single) (11)	0.7	0.46	65	78
Household income (<1500/month) (11)	0.7	0.45	60	72
Patient's condition (bedbound) (11)	0.6	0.41	108	130
Duration of caregiving (<2 years) (38)	0.7	0.4	45	54

Table 2: sample size calculation for objective 2

Therefore, the largest sample size calculated to be used in this study is 130.

4.8 Research Tool

4.8.1 Stroke Patients' demographic data

Questionnaire structured on the socio demographic factors such as age, sex, ethnicity, duration of stroke and patients' condition (bedbound/not bedbound).

4.8.2 Caregivers' demographic data

The data collected were age, sex, ethnicity, education level, marital status, occupation, family income (per month), relationship with patient, duration of care (months), duration of care (hours/day), living arrangement, caregiver's type of responsibility towards patient, receive informal help, receive formal help, and caring for others.

4.8.3 The Zarit Burden Interview

The Zarit Burden Interview (ZBI) is a 22-item instrument for measuring the caregiver's perceived burden of providing family care. The 22 items are assessed on a 5-point Likert scale, ranging from 0 = 'never' to 4 = 'nearly always'. Item scores are added up to give a total score ranging from 0 to 88, with higher scores indicating greater burden. The questions focus on major areas such as caregiver's health, psychological well-being, finances, social life and the relationship between the caregiver and the patient.

4.9 Data collection

The stroke patients were identified during their outpatient follow-up at Klinik Rawatan Keluarga, HUSM during the period from December 2012 to May 2013.

4.10 Operational Definitions

1. Caregiver defined as the unpaid person closely involved in physical (feeding, bathing, toileting, walking) and emotional care (empathic listening, encouragement and motivation to adhere to treatment)
2. Caregiver burden refers to a high level of stress that may be experienced by people who are caring for another person (usually a family member) with some kind of illness.
3. Bedbound refers to patients cannot get out of bed without the assistance from another person.
4. Formal support refer to paid service by a nurse or a maid who was privately employed to provide assistance and supervision of the activities of daily living of the patient or involved in doing other household chores for the patient or the caregiver.
5. Informal support refers to as family members, friends and neighbours who provided emotional and physical support to caregivers.

4.11 Statistical Analysis

Data was entered and analyzed using Statistical Program for Social Sciences (SPSS) version 22. Data checking and cleaning were performed before analysis.

Objective 1 was to ascertain the level of burden among caregivers of stroke patients. The mean and proportion of caregivers involved in that particular activity was calculated, and was expressed as mean (SD).

Objective 2 was to identify the associated factors of burden among caregivers of stroke patients attending Klinik Rawatan Keluarga, HUSM. The dependent variable was burden score. The independent variables for patients were age, duration of illness (months), gender, ethnicity and condition of the patient. The independent variables for caregivers were age, income, care duration (months), ethnicity, gender, education, marital status, occupation, relationship with patient, care duration (hours), stay with patient, informal support, formal support and other responsibilities.

The analyses for this objective comprised of Simple Linear Regression which was used to determine the associated factors of caregiver burden; and Multiple Linear Regression which was used to determine the predicted associated factors of caregiver burden while controlling for other confounders in the model.

The procedure of Multiple Linear Regression analysis

The distribution and frequencies were examined. All continuous variables (patient's age, duration of illness, caregivers' age, income and care duration) were expressed as mean (SD) since there are no skewed data. Categorical data were presented as frequency and percentage.